

Improving care home life for people with Parkinson's

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Abstract

Background: There are few previous data on the experience of living in a care home for people with Parkinson's disease (PwP).

Aim: To explore the experiences of PwP living in care homes in North-East England.

Methods: We conducted in-depth interviews within a cohort recruited to a larger study for all people with late stage Parkinson's. Interviews were conducted by a psychology trainee and analysed thematically

Findings: Ten PwP and two family members were interviewed. Key concerns were the lack of time to consider the move to a care home, loss of independence, meaningful social contact and concerns over staff knowledge of Parkinson's, particularly in relation to medication.

Many PwP recognised the pressure felt by care home staff, and after allowing for this, reported many positive experiences.

Conclusions: Greater awareness by staff of symptoms and PwP's concerns, particularly in relation to medication, may help to improve care home experience.

Key Words: Parkinson's disease, care homes, qualitative, medication

Key points

- There are few previous data on the experience of people with Parkinson's disease living in care homes.
- Admission to care home was often rushed with very limited choice of where to go.
- Loss was a major theme, both in terms of loss of relationships and loss of independence.
- Awareness of Parkinson's symptoms by care home staff was a major concern, particularly the fluctuating nature of the condition.
- Understanding the importance of medication in Parkinson's by staff was also seen as a major contributor to good experience.

Reflective questions

- How can we better support individuals who are moving into a care home?
- How can we identify ways to help individuals manage the transition of moving into a care home and coping with loss?
- How can care home staff be better supported to understand the variability in Parkinson's symptoms and the effects of medication?

BACKGROUND

In the United Kingdom (UK), Parkinson's disease (PD) is the second most common neurodegenerative condition. It is progressive and often fluctuates, with a wide range of motor and non-motor symptoms (Alves et al. 2008). This gives rise to complex and ever changing care requirements as the disease progresses and drug treatment becomes less effective. People with PD (PwP) may require support, often from an informal carer (e.g. wife, sibling, son or daughter), to assist them in many everyday activities and help maintain a reasonable quality of life (Aarsland et al. 2000; Porter et al. 2010). However, with disease progression, the burden on the informal carer is often unsustainable, and their quality of life frequently suffers (Greenwell et al. 2015). In late stage disease, a breaking, or crisis, point is often reached when the carer acknowledges they are no longer able to cope and other care options need to be explored, such as residential or nursing home placement.

Data on the lived experiences of PwP within care homes, and the decision-making process around the time of placement are scant (Armitage et al. 2009; Barnes et al. 2006; van Rumund et al. 2014). Across the general elderly population, a recent report "What's it like to live in a care home?" by Healthwatch (Healthwatch 2017) collated a number of reports on care homes throughout the UK. They identified two lessons that care homes could focus on to improve the residents' experiences; 1) treat residents as individuals and ensure all their needs are met and 2) seek feedback, act on it, and be open. Individual experiences of some residents were reported and highlighted issues including dignity and choice, staff numbers, training and turnover.

This study aimed to explore the decision-making processes at the time of placement and the experiences of care homes residents with PD.

METHODS

This study was part of the larger Northumbria Care Needs Project (NCNP) (Hand et al. 2016). The study was a qualitative, experiential account of PwP living in care homes that was nested within the larger NCNP. To meet inclusion criteria for this study individuals met the inclusion criteria of the NCNP, participants were: under the care of the Northumbria Healthcare NHS Foundation Trust PD service, had a diagnosis of idiopathic PD (IPD) at Hoehn and Yahr (H&Y) stage III-V, and those with Cortico-Basal Degeneration (CBD), Multiple System Atrophy (MSA) or Progressive Supranuclear Palsy (PSP), living either at home or within a care home. Individuals were excluded from the NCNP if they had a diagnoses of Lewy body dementia, vascular parkinsonism or drug induced parkinsonism due to the differing aetiology of these conditions. Inclusion criteria for this study were: taking part in the NCNP and living in a care home. Individuals were excluded if they did not have capacity to consent. As, inclusion of people lacking capacity was not deemed appropriate, given the need to conduct in-depth interviews.

Ethics

Ethical approval for this study was obtained locally from Newcastle and North Tyneside 1 research ethics committee (ref: 14/NE/1093). For those who were eligible, the study was explained verbally and in writing to all potential participants and, if they were willing to participate, informed, written consent was obtained.

Setting and participants

This study was completed in the catchment area of Northumbria Healthcare NHS Foundation Trust (Northumberland and North Tyneside in North-East England). The Trust's PD service manages around 1400 people with PD and related conditions.

Of all PwP under the care of Northumbria Healthcare NHS Foundation Trust PD service 377 met the inclusion criteria for the NCNP (Hand et al. 2016), of whom 91 (24.1%) were living in care homes, of whom 24 (26.4%) were recruited to the NCNP of these 24, 16 had capacity to consent and were approached for this study and invited to interview.

Family members were not the primary focus of the research, however, where family members requested to join the interviews they were included when the PwP consented.

Data collection

Data collection took place between 3rd September 2015 and 1st February 2016. LO, a psychology trainee with experience of conducting qualitative research, conducted the in-depth, semi-structured interviews. Interviews were audio recorded and contemporaneous notes were maintained by the researcher. Post-hoc field-notes were written documenting the interviewer's impressions and reflections. PwP were interviewed alone, or with family present, at their place of residence. Time was spent making introductions, explaining the study and building rapport prior to starting the interviews as suggested by Ryan and Dundon (2008). Semi-structured interviews were conducted with an interview guide to assist in the exploration of the PwP's experience of care home placement, support, decision making and general experiences of the transition from own home to care home.

Sampling continued until data saturation was reached. Data saturation was considered to be the point at which no new ideas were being revealed (Mason 2010). Where family members, when agreed by the PwP, requested to take part in the research; separate interviews of the PwP and carer were organised where this was agreed to be more appropriate.

Data Analysis

All checked and cleaned data were stored on an encrypted server. Background demographic and disease specific data were summarised using standard descriptive statistics. Audio

recordings were transcribed verbatim by LO and an administrative assistant. Transcripts were manually categorised and thematically analysed using the following steps; familiarisation, constructing initial thematic framework, labelling and sorting, reviewing data extracts and writing up (Braun and Clarke 2006). Strategies to improve credibility and trustworthiness in analysis were used. Two researchers (LO and LD) independently coded the data and differences in codes and themes were discussed before being presented to the rest of the research team for agreement.

FINDINGS

Of the 16 PwP who met inclusion criteria and were approached for interview: two people agreed to an interview and died before an interview could be arranged, one individual declined to be interviewed, which left a potential interview cohort of 13. Data saturation was reached after interviews with 10 PwP and two family members (one husband and one daughter). Eleven interviews were completed (one interview was conducted with both the PwP and their husband together at their request). The PwP lived in eight different care homes, and their profile is summarised in **Table 1**.

Thematic analysis

Four themes and two subthemes were developed: (i) Loss; (ii) Why I'm here; (ii_a) Care home choice; (iii) Transition, adjustment and adaptation; (iv) Care home life (iv_a) Medication: timing, control and the impact on PwP.

Theme I. Loss

Loss was described in a number of interviews in terms of: 1) loss of independence and; 2) loss of relationships, although these aspects were inter-related.

“I would like it if... I could go out on my own sometimes just for a walk, you’ve always got to have somebody with you. I have got quite a few friends that I would like just to be able to walk down and visit them instead of them having to come every week to see me, you feel hospitalised.” (CH001)

Increasing functional loss, more frequent falls and the fear of falling as the disease progressed were linked to the loss of independence and contributory factors to care home placements (Theme II). The opportunity to cook or go shopping freely was lost and care home policy now governed their lives. In some cases varying levels of independence combined with the fluctuating nature of the disease meant that needs were not always met.

“...I’m independent but sometimes I carry my independence too far. Like this morning, they showered me and just left me and it would have been a help if they’d kind of got me ready properly.”(CH002)

Decision making and financial management was done by family members and homes were often sold to fund care home placements. There was a mixed response about what it was like to give power of attorney to a family member. In most cases the change wasn't stressful and respondents often felt like it made life easier, but some felt it was a further loss of independence.

“It was funny at first, I kept thinking I didn’t know if I like this idea but then I couldn’t manage, I couldn’t hardly hold money never mind have it.I just think... let her take the burden.” (CH001)

“Hellish, it takes your, a bit of your, manhood away from you, it takes away your... Independence.” (CH004)

The death of a husband or wife often precipitated the need for care home placement and many discussed the difficulty in coming to terms with bereavement whilst coping with adjustment to care home life. After placement respondents also talked about the deaths of friends and family outside the care home and of the difficulties of making new friends within a care home only to see them die soon afterwards. Respondents talked about their experiences of relationship losses in the context of social isolation, with a changed social circle and reduced social contact, particularly having only limited contact with someone they had previously spent every day with, such as a spouse. A number of types of relationship losses were explored and when combined with aspects of independence loss, changes of roles were also apparent. Stopping work and hobbies, no longer owning a home and going from carer to being cared for were forms of loss discussed.

“...it’s changed the relationships [with my daughter] from being the one who has been the carer has changed to being cared for. Nice in the fact that I know they want to do it, but not so nice the fact that I’ve had to give up that role.” (CH023)

Theme II. Why I’m here

Factors contributing to care home placement split into two distinct areas; those contributing to the decision to move into a care home and those involved in the care home choice, once the decision to move had been made. The former explored physical decline and increasing difficulties at home. Motor symptoms, such as reduced mobility, and non-motor symptoms, such as cognitive decline, meant that individuals required increasing amounts of support for domestic tasks (e.g. cooking, cleaning) and personal care (e.g. washing, toileting and dressing). Formal care support and the help of family members and/or friends often ameliorated these changes and allowed the PwP to stay at home. Eventually, in many cases, an episode, such as a serious fall resulting in hospitalisation, occurred that acted as a catalyst for the need to review care requirements for safety reasons.

Frequent discussions about family concerns were mentioned, but less frequently a conversation was held regarding how best to meet care needs going forward. Such discussions only occurred after a serious fall or a noticeable change in circumstances. These conversations were often initiated by family or professionals. In some cases the burden of care at home just became too much.

“She was ill at home and I looked after her for maybe 6-9 months, but it got too much for me...She was up through the night and one thing and another... Lack of sleep, yes. I was more or less doing everything for her.” (CH008a)

Subtheme IIa. Care home choice

Choice of care home was often influenced by whether the process was rushed, as a result of emergency hospitalisations, or whether more time was afforded. Care home availability, bed space and locale all influenced the decision. There was a strong desire to have family close

by. Another influence was a recommendation from family or friends of a home or knowing someone already in a particular care home. In some cases offspring moved parents closer to them from other areas of the country. One thing that was often discussed was a lack of time to think about the decision. In many cases, when the move to a care home was the result of a hospitalisation, the PwP did not get to see the care home they were going to move into. In these cases family members were responsible for identifying a suitable care home and working with social workers to arrange and address any funding issues. Often the response to “what made you choose this home?” was that “they had a bed.”

Some PwP had lived in more than one care home. Reasons for moving care home varied from home closures, needing to move to nursing from residential care, knowing residents or staff at the home or that it was closer to family. Sometimes PwP took a room that was not as nice, but meant they could move closer to family, with the expectation that a nicer room would soon become available; this created additional pressure on PwPs to make decisions out of fear of ‘losing’ a placement.

Theme III. Transition, adjustment and adaptation

Since PD is progressive, regular, on-going adjustments and adaptation (relying more on family to meet care needs, need for formal care input, home adaptations) were an established part of life, long before care home placement.

Within the care home, adaptation and adjustment was tied to elements of loss, but was an important and on-going factor in coping and overcoming the loss. Moving into a care home and becoming used to the idea that the move was permanent didn’t come easily for all of the PwP. Some simply accepted that this was now where they lived, but not all would say it was ‘home’.

“It was alright, but every now and again I kept thinking, when am I going to go home? They just kept telling me, you are home, this is your home now and every time they said that I got more and more upset. I didn’t want it to be my home.” (CH001)

Adjusting to new routines, living with others, having others make decisions for them, whilst managing changes in symptoms, was a new challenge.

“...having to rely on somebody else for everything, if I need to go to the toilet I have to wait until somebody comes and helps me, that sort of loss of personal dignity is the most difficult thing.”(CH023)

Moving into a care home meant living with many people in a much closer space than they were used to in their own home. In some care homes residents are all kept together in day rooms. Some respondents described how it wasn’t always easy to make friends or converse with other residents, who often had memory issues, meaning their main opportunities to converse with others were the staff or when they had visitors.

In some cases, respondents had moved between a few homes. This was described as starting out all over again with new routines, people and rooms, but not feeling in control of those decisions if the care home closed or a move was made as a result of financial changes.

“I think that people would find that the hardest... routines, making new friends and going through the whole lot again. I wouldn't want to have to go through it again mind, but you've got no choice in the matter.” (CH004).

Theme IV. Care home life

PwP talked extensively about what impacted on their experience of living within the home. Visits from family and activities were things respondents enjoyed. Being able to use the gardens and having a choice of good quality food were seen as positives. Interactions with care home staff greatly influenced the sense of homeliness and inclusion both positively and negatively.

“The way that the nurses [care home staff] were, they helped an awful lot; the fact that it was local people that were running the hospital [care home]. Right from the top to the bottom you had this homeliness all the way through.....and it was just home from home.” (CH004)

Communicating with other residents wasn't always easy. Consequently, many respondents found the thing that they most enjoyed about the home, or the aspect that could most improve, was having time with staff. PwP explained that having 10 minutes to talk to staff was what they valued the most. In instances where this wasn't happening PwP and family members were quick to highlight that it wasn't the fault of staff and that they were working very hard under obvious pressure. They felt with more staff the burden would ease and the all-round feel would improve.

“Yes, it would be nice if they had more carers than the ones that are here and would have more time to talk, sit and talk for half an hour. They are always so busy, they do their best and on the whole they are extremely good...” (CH023)

Having a sense that the staff understood how PD affected them personally was important, it helped them feel safe.

“The other places I’ve been to there was no mention of it [PD}, they didn’t seem to know anything about Parkinson’s but this place does... I feel better about it. I was always frightened that I would get the wrong tablets [in previous homes]...” (CH001)

Knowledge of PD and communication between staff were recurrent factors, with differences in care quality within a home between permanent and agency staff a particular concern that impacted on feelings of security.

“They change a lot here because they hire a lot of agency people. Sometimes they don’t understand about Parkinson’s... they don’t understand at all.” (CH002)

It was felt that when less was known specifically about their needs, and the fluctuating nature of PD, they suffered more from their symptoms. It also meant that, as there were periods of time when they needed less support, some staff did not realise when they needed more.

During one interview the PwP had a cup of tea. At the time her tremor was very pronounced and she asked if the interviewer could get her a straw out of a drawer. She explained that

when she is wearing off medication it can be very difficult to have a drink, since even getting a straw from a packet is problematic (due to the tremor), and staff have little time to help.

Subtheme IVa. Medication: timing, control and the impact on PwP

The need to get the correct medication, in the correct dose at the correct time was frequently discussed. Respondents spoke about what it was like to go from having responsibility for their medications to having that taken away from them. Some found that it took away more of their independence whilst others found that it relieved a burden. In most cases medication was well managed by staff and on time. Nevertheless, when errors did occur, this had a major impact on functional ability and quality of life and these effects could last for a number of days. During one interview a staff member came in to bring the person their 11am medication at 11:45am. Respondents reported that not being believed when they raised concerns about their medication left them feeling frustrated and not heard.

“I say I don’t get enough tablets regular. They say I do, but I put them down in the book every time I get them. Some nights I don’t get any...” (CH008)

DISCUSSION

There is very limited previous research of the experience of PwP in care homes, and it has tended to focus on the complexity of the care needs, staff knowledge and training needs. Armitage et al. (2009) explored the perceptions of care home residents with PD and their close relatives and reviewed care plans. They detail an apparent shortfall in the knowledge and understanding of PD among care home staff as well as the need for flexibility in routine to meet the dynamic needs of PwP. In the Netherlands, van Rumund et al. (2014), conducted

semi structured interviews with PwP in care homes and informal carers to explore unmet needs and experiences. They also used focus groups with nurses and other healthcare professionals to explore barriers to care for PwP. Three core unmet needs were highlighted; 1) unsatisfactory empathy and emotional support; 2) insufficient staff knowledge on PD-related issues, such as motor fluctuations, leading to medication issues; 3) suboptimal organization of care with limited access to neurologists and specialized PD nurses. These findings are broadly supported within the study sample in the current research. PwP experiences of care homes may be similar to that of people without the condition, but the combination of motor and non-motor symptoms, and their fluctuating nature, make the issues faced by many PwP, and those caring for them, uniquely challenging in a setting, often designed to provide a relatively standardised level of care for everyone.

The Healthwatch report (2017) comments on the pressures within care services in the UK, with time pressures meaning staff were unable to deliver the sort of person-centred care that is seen as an ideal. This was particularly true for the PwP cohort sample in the current study. Busy care home staff may struggle to respond adequately to changes in presentation as the disease fluctuates. Nevertheless, the Healthwatch report notes that, *“The quality of care varies between homes, but also within homes, and too few homes get the basics right every time.”* Findings in the interviews conducted support this view and emphasise the fact that providing the basics well (e.g. getting the correct medication on time) can have a huge impact on the care home experience. For PwP, getting medication on time can help avoid unnecessary fluctuations in function and promote independence, reducing the burden on care home staff. As such, the ‘Get It On Time’ initiative by Parkinson’s UK (2018) should be promoted in care homes and the need to ensure timely medication administration to PwP should be seen as an essential element of basic care. At times of relative independence in activities of daily living, there may be opportunities to promote self-efficacy and minimise

the sense of loss. With regard to medication, communication, both between staff and between staff and PwP is of central importance. In many cases of medication errors reported here, it is possible that changes to medication had been made by a doctor or nurse, but not effectively communicated to the PwP. If this is the case, staff must inform the PwP and offer reassurance to avoid leaving them feeling worried.

In terms of what makes a good care home, the resounding message from the study cohort was staff time and staff continuity. If staff were able to make time to talk and interact with them about life outside the home, this was seen as an enormously positive experience. This was sometimes the only opportunity they got to have a meaningful conversation with someone, other than during occasional family visits. However, increased staffing levels would be needed to allow staff the time to engage in conversation with residents routinely (Healthwatch 2017).

The theme of transition, adjustment and adaptation is particularly pertinent to PwP. Many PwP have lived with change specific to their condition since diagnosis, they have made adjustments to continue to live at home, but often discussions and thoughts about future care were not considered. Opening discussions with PwP and their families about care home placement within the context of change may help many to come to terms with the need to consider future care arrangements. Nevertheless, it may not always be possible to make firm plans. Often a hospitalisation was the catalyst to a care home placement. At this point, the lack of true choice in care home placements was apparent. In rural areas there may only be small numbers of homes that can meet their needs, and that have room availability. When coupled with a desire to be close to family, this often puts people under increased pressure to accept what is available. Facilitating care planning discussions as early as possible may help to ensure a smooth transition and a greater choice of care homes.

Limitations

This study was only conducted in the North East of England, although the PwP interviewed are likely to be relatively representative of the UK as a whole. Only a small number of PwP were interviewed, however no new codes were being generated. Many of the interviewees had cognitive impairment so they might not remember aspects of their transition to care home placement but we cross checked these with hospital data. There were few family members included in the research. Future designs would benefit from specific recruitment of family members to provide further circular information on the processes involved in care home transition. The authors acknowledge that not all participants' comments are presented here within the themes. The data presented here was selected as certain participants were able to express their opinions more eloquently than others, indeed, it was felt that data presented would enhance readability and contribute to the narrative.

Conclusions

This study provided an insight in to participants' experiences of care home placements and living in the North East of England. Participants highlighted that not getting medication on time and lack of staff knowledge about PD were major concerns, which related to key themes of loss (e.g. of independence) and transition and adjustment and adaptation (e.g. to fluctuation in, and progression of, symptoms and to care home life). The study also identified more general problems with low staffing levels and a lack of social interaction for participants. For many, making decisions about care home placement felt rushed. Increased support from health and social care services before individuals need to move to a care home may help to smooth the transition and increase self-efficacy.

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Table 1. Profile of participants

Mean age	83.1 years (SD 7.0774, range 72 to 93)
Sex	6 Female, 4 male
Hoehn and Yahr stage	3 stage III, 6 stage IV, 1 stage V
Median disease duration	10.5 years (IQR 6 to 18), range 4 to 26).
Marital status	7 widowed, 2 married, 1 single
Type of care home	7 residential care, 3 nursing care
Admitted to current care home from	4 From hospital, 3 own home, 1 next of kin's home, 2 from previous care home
Funded by	2 by UK NHS, 4 self-funded, 4 missing data
Mean age admitted to a care home	79.6 years (SD 8.1755, range 65 to 91)
Median number of months in a care home	26.5 (IQR 18.8 to 73.7, range 12.0 to 75.3)

SD = standard deviation, IQR = interquartile range